WORLD
ATOPIC ECZEMA
DAY

PATIENT ORGANIZATION

World Atopic Eczema Day

TOOLKIT 2025

Our Skin, Our Journey

#AtopicEczemaJourney

International Alliance of
Dermatology Patient
Organizations

GLOBALSKIN.ORG

EFA

European Federation of Allergy and Airways
Diseases Patients' Associations

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Awareness for Atopic Eczema

Atopic eczema (AE) is a common relapsing, chronic skin disease impacting people of different ages. The disease causes a heavy burden of pain, social, emotional and economic impact for patients, and for society as a whole. However, the tendency of dismissing the disease as “just a rash” is still highly persistent in society.

Aside from the physical burden, Atopic Eczema may also have far-reaching effects on the patients’ ability to work and perform at work and school and to sleep. It can profoundly affect self-image, their emotional and social interactions and the way that others in society respond to them. Understanding the burden of Atopic Eczema is critical for better care, disease management and information to improve the lives of patients and caregivers.

Campaign Theme 2025: Our Skin, Our Journey

The global Atopic Eczema community comes together on September 14th to raise awareness for the disease; to speak up about the burden it has on patients and caregivers and to recognize the need for care and treatment that is reflective of the multidimensional nature of the disease.

The patient journey of people living with Atopic Eczema can be a life-long rollercoaster. As a chronic disease that starts in childhood and evolves across life, patients experience its ups and downs in the shape of painful flare-ups and relapses. The skin presents people to life, and for people with AE it testifies about their patient journey to control their AE and live with it.

The theme "**Our Skin, Our Journey**" aims at raising awareness about life with AE, and federates patients' struggles in their daily fight for better care. Building on previous WAED edition, the 2025 theme provides with a platform that boosts patients’ lived experiences with a disease that constantly evolves. The theme is collective (“our”) and enables to connect with the global community of patients and fosters positive narratives. “Our skin, our journey” is a versatile platform theme that can integrate any specific local and individual request or story that can be defined at local level.

This 2025 World Atopic Eczema Day Toolkit has been developed by the European Federation of Allergy and Airways (EFA) in partnership with the International Alliance of Dermatology Patient Organizations (GlobalSkin). Inside you will find the messaging for World Atopic Eczema Day 2025 and other tools that will guide your national World Atopic Eczema Day campaign.

Feel free to localize your content to better resonate with your audience. Adapt messaging and data to reflect your country or community’s context. For example:

- Translate key phrases and hashtags into your local language(s), while also keeping the hashtags in English to connect globally.
- Use local statistics or patient stories to make the impact of Atopic Eczema more relatable and compelling for national media or policymakers.

Campaign hashtags

Please use campaign hashtags in your social media posts – this connects your local campaign to others across the world that are participating! Help to amplify the message on a large scale. Campaign hashtags can be translated into national languages. Please use at least one hashtag in English to connect with the global conversation on the day.

#AtopicEczemaDay

#AtopicEczemaJourney

How to participate in World Atopic Eczema Day

Participating in the day can help you achieve your local goals

Before you start organizing your participation in World Atopic Eczema Day, you might wish to reflect how the activities can support the overall work of your association. For example, you could be active during the day to support your broader atopic eczema objectives, such as:

- **Community building**: programme an activity on the day to strengthen connections among people living with atopic eczema, their families, and carers through shared experiences, mutual support, and collective identity.
- **Awareness raising**: join the day to increase public understanding of atopic eczema and its impact on daily life, highlighting the physical, emotional, and social burden, and sharing facts, myths, and patient testimonies.
- **Visibility and media engagement**: participate in the international day to put AE on the map by gaining visibility in traditional and digital media.
- **Education**: join the day to develop and amplify your trusted, practical, and empowering information to patients, carers, and the general public about living with AE.
- **Advocacy**: use the day to start a conversation with policymakers and health authorities to push for better recognition, resources, and care for people living with AE, adapting the requests to the most pressing needs in your own country.
- **Fundraising**: organise an activity on the day to raise funds to support patient services, research, awareness campaigns, or the sustainability of the organisation itself.
- **Partnership development**: invite stakeholders such as healthcare providers, researchers, and companies to join the day and collaborate.

Mobilise your audiences for AE support as a patient organisation

For patient organisations, “Our Skin, Our Journey” is an opportunity to celebrate the evolution of the organisation, its milestones, impact, and the collective work and efforts of the community of patients and caregivers. Below are some ideas to highlight the journey of patients involved in AE organisations:

- **Spotlight** stories from your community: like the flare-ups and the support received, or the one patient that volunteered for the organisation, how each story symbolizes the journey the organisation has walked with them.
- **Develop** a carousel or story series showing turning points for your organisation like the first AE event hosted, the first grant received and how it supported your organisation, your patient education materials, or showcasing your organization in action as you advocate for AE with the government.
- **Share** positive stories of how your organisation has supported patients throughout their individual patient journeys, to find the right specialist and treatment.
- **A timeline-style post**/video showing key achievements: awareness campaigns, policy wins, support groups launched, etc.
- **Share** the story of how the organisation was formed by patients and families, and how it grew into a local/national voice.
- **Reach out** to medical societies or individual professionals and encourage them to share and support your messages around World Atopic Eczema Day. You will find here a template letter you can use.
- **Use statistics** to reinforce your messages, especially if you have local data:

1. Only 15% of European Atopic Eczema patients are highly satisfied with their current treatment [1]
2. 1 in 4 European patients feel that they cannot cope well with their atopic eczema and that they are not able to keep it under control [1]
3. 45% of atopic eczema patients in Europe have their social life and leisure activities restricted by the disease [1]
4. 927,12€ the average annual amount patients pay for their atopic eczema treatment in Europe [1]
5. 95% of surveyed patients have out of pocket expenses related to the condition [1]
6. According to the World Health Organization, more than 230 million people have Atopic Eczema [2]
7. 62% of patients and caregivers see a holistic treatment plan as their number one care priority [2]
8. Over 25th of patients and caregivers do not know where to find health care to manage Atopic Eczema [2]
9. 50% of surveyed patients have to pay out-of-pocket for basic treatment prescribed by a medical professional [2]
10. According to the Global Burden of Disease Study, Atopic Dermatitis is the skin disease with the highest disability-adjusted life year (DALY) burden and ranks in the top 15 of all nonfatal diseases [3]

Share your testimonial as a patient or caregiver

As a patient or caregiver, your contribution to World Atopic Eczema Day can serve to highlight the physical, emotional and practical aspects of living with Atopic Eczema, from diagnosis to daily management. Find some ideas below:

- **Celebrating small victories:** finding a supportive dermatologist, discovering a helpful product, or gaining confidence in one's skin can be life changing moments in the journey of a patient.
- **Patients can share their experience of growing up with AE**, focusing on achievements and learnings.
- **A carer (parent or partner) explains daily routines** involved in supporting someone with AE: skincare, emotional support, and navigating the healthcare system.
- **A teen or adult patient reflects on the early days of their diagnosis** and gives practical tips for those just starting their journey.

Tips on how to engage your audiences

Tips for involving policy makers in marking World Atopic Eczema Day

Mobilising relevant stakeholders and policymakers in your countries and involving them in the celebration of the day can be a highly effective way to increase the impact of your actions and amplify your messages. This is also an opportunity to start connecting with relevant policymakers and developing a relationship for follow up about more concrete asks. Here are some tips on how you could reach out to and involve policymakers in your World Atopic Eczema Day activities:

Reach out well in advance (at least 6–8 weeks ahead) and **be specific** about what you're asking: attending an event, sending a video message, signing a statement, or setting up a meeting.

Send a personalised letter or invitation: Highlight **why AE matters** in your country and mention **how their support can make a difference** to patients and families.

Include a **brief factsheet or impact statement** about AE in your country to make the issue more tangible.

Invite them to record a short video message. Ask them to share a message of support for AE patients, acknowledging their challenges and the importance of awareness. Provide a **script suggestion** or a few talking points to make it easy.

Invite them to your awareness event. Whether it's a panel discussion, patient storytelling event, or community walk – invite policymakers to attend and speak. Position them as **champions of patient voices** and acknowledge their role in creating supportive policy.

Ask them to sign a public statement or pledge. Create a simple declaration of support for AE patients and ask policymakers to endorse it. Use it as a tool for media outreach and social media momentum.

Create a photo opportunity. If they attend your event or meeting, take a photo with AE advocates and share it on social media. Use branded materials (banners, T-shirts, posters) for visibility and campaign identity.

Amplify their support. Tag their accounts when sharing their video or participation. Thank them publicly and highlight their involvement in press releases and newsletters – this can encourage further engagement.

Tips for reaching out to media

- **Craft a strong press release, announcing your World Atopic Eczema Day activities:** events, notable speakers (including policymakers), patient stories, or awareness campaigns. Add a compelling headline, a strong quote from a patient or organisation leader, and contact information for follow-up.

- **Pitch human interest stories:** the journey of someone living with AE, a parent advocating for their child, or a success story in treatment. Journalists are drawn to real, emotional stories that illustrate wider health issues. Make sure patients are comfortable sharing publicly and are available for interviews.

- **Leverage policymaker involvement.** If a policymaker records a message, attends an event, or signs a pledge, include it in your media outreach; their involvement adds credibility and media appeal.

- **Plan photo opportunities:** patient with a policymaker, awareness walk with branded T-shirts, or a symbolic gesture (e.g. lighting a landmark in campaign colors). Offer high-quality images and video clips to the media, especially if they can't attend in person. Share these visuals on your own social media too, tagging media outlets and using the campaign hashtag.

- **Offer experts for interview** with dermatologists or healthcare professionals, organisation leaders, patients willing to share their story. Provide media with a media kit: bios, photos, suggested questions, and key messages.

- **Emphasise** the local relevance, local prevalence rates or lack of services, local hospitals, clinics, or professionals involved, actions or calls to change regional/national policies.

Build a targeted media list including:

- Health and lifestyle journalists
- Local newspapers, radio and TV stations
- National media with a focus on health or policy
- Use social media to attract media attention. Post engaging content: video messages, patient quotes, event teasers, and live updates. Tag media outlets, journalists, & influencers.
- Follow up with media. A few days after sending your press release, follow up with a quick call or email.

Create a media toolkit with:

- Press release
- Fact sheet on AE
- Event/program details
- Patient and policymaker quotes
- High-resolution images or videos
- Contact details

Online patient advocacy tips to participate in the #AtopicEczemaJourney Campaign

Whether you live with eczema or atopic dermatitis, care for someone with the condition, or are already actively involved with a patient association, your voice is important!
Patients need your support on World Atopic Eczema Day 2025 to ensure that the needs of the atopic eczema patient community are heard and understood at the European and national level.

How to enact positive empathy on social media platforms

Positive empathy occurs when users understand, share and care about the emotions of other people.

- **Know your audience:** patients, decision-makers, healthcare professionals, civil society organisations. Tailor your content, tone, and style to the needs and expectations of each group.

- **Share the toolkit:** Together with GlobalSkin, EFA has developed a toolkit for World Atopic Eczema Day 2025. The campaign hashtags are #AtopicEczemaJourney and #AtopicEczemaDay.

- **Encourage interaction:** Share content that sparks conversations, engagement and collaboration in the patient community and outside of it with the use of compelling messages and visuals.

Rules to promote disease-specific content on social media platforms

When it comes to promoted posts on Meta platforms (Facebook, Instagram, WhatsApp), there are rules to be aware of to avoid rejection or blocked content.

- Meta wants all users to follow their local laws, be fair, and not promote things marked as illegal or harmful.
- Meta wants ads to be pleasant and not shocking, violent or inappropriate; e.g, visuals of human body parts or fluids might be rejected.

Important to remember what falls under objectionable content:

- Disturbing, sensational or violent content
- Promoting negative self-perception to sell products or services

What to do if your boosted post was rejected?

There are two options:

- You can edit or create a new ad to align with the policy you've violated
- You can Request another review of your ad

Remember that just duplicating the ad won't resolve the issues with it and it may be rejected again. Keep in mind to review the copy, the image and the Landing page it redirects to, making sure it's aligned with Facebook's Advertising Policy.

Precautions on patient advocacy

- Wording and visual content should be carefully defined. Do not use direct, graphic images of body parts with atopic eczema or fluids to avoid rejection when boosting a post. Words e.g. "bleeding" or statements e.g. "not contagious" might result in blocked content.
- Excessive empathy in messaging might provoke "the feeling of being sorry" instead of encouraging the audience to participate in the call to action.
- Always consider consent and privacy when sharing stories or images online. Ensure that patients or caregivers have given clear, informed permission before posting their personal experiences or photos. This includes consent for visuals, especially if they show identifiable individuals or sensitive health details.

How to share your personal story – individual patient advocacy

By sharing your personal story, you humanize the disease itself and the journey patients are going through. Sharing it helps build trust and credibility among the atopic eczema community and wider audience such as healthcare professionals, decision makers and civil society organisations.

(Cont'd) How to share your personal story – individual patient advocacy

- Download the toolkit to find support in making atopic eczema and its impact on patients better known and understood.
- Use #AtopicEczemaDay and #AtopicEczemaJourney in your messaging to join the global
- movement on the day.
- Share your message with a visual proposed in the toolkit or your own. Consult the rules to promote disease-specific content on social media platforms.

Remember that sharing your information online might result in misuse, reproduction or distribution of this information by third parties.

Accessibility Considerations

Keep accessibility in mind when sharing content online. Make sure your posts can be understood and enjoyed by everyone, including people with visual impairments or other disabilities. For example:

- Always add alt text in post captions so screen readers can describe them to users.
- Avoid text in images: Use real text instead of embedding text in images when possible, as screen readers can't access image-based text.
- Ensure high contrast between text and background in your visual materials
- Do not rely on color alone to convey meaning
- Provide captions for videos and transcripts for audio
- Use descriptive link text (avoid "click here" or "read more") and make it clear where a link will lead.

Templates

- Template Press Release
- Template Support Letter to Medical Societies and Individual Healthcare Professionals
- Template letter to Ministries

References

[1] EFA, European Federation of Allergy and Airways Diseases Patients' Associations (2018). Itching for life: quality of life and costs for people living with Atopic Eczema in Europe.

[2] GlobalSkin Atopic Eczema Patient & Caregiver Survey, 2020

[3] Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. (March 2021). "The PRISMA 2020 statement: an updated guideline for reporting systematic reviews". BMJ. 372: n71. doi:10.1136/bmj.n71. PMC 8005924. PMID 33782057.

Thank you!

Your voice can help make a real difference to the atopic eczema community.

If you have any questions, please do not hesitate to contact the team at:

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